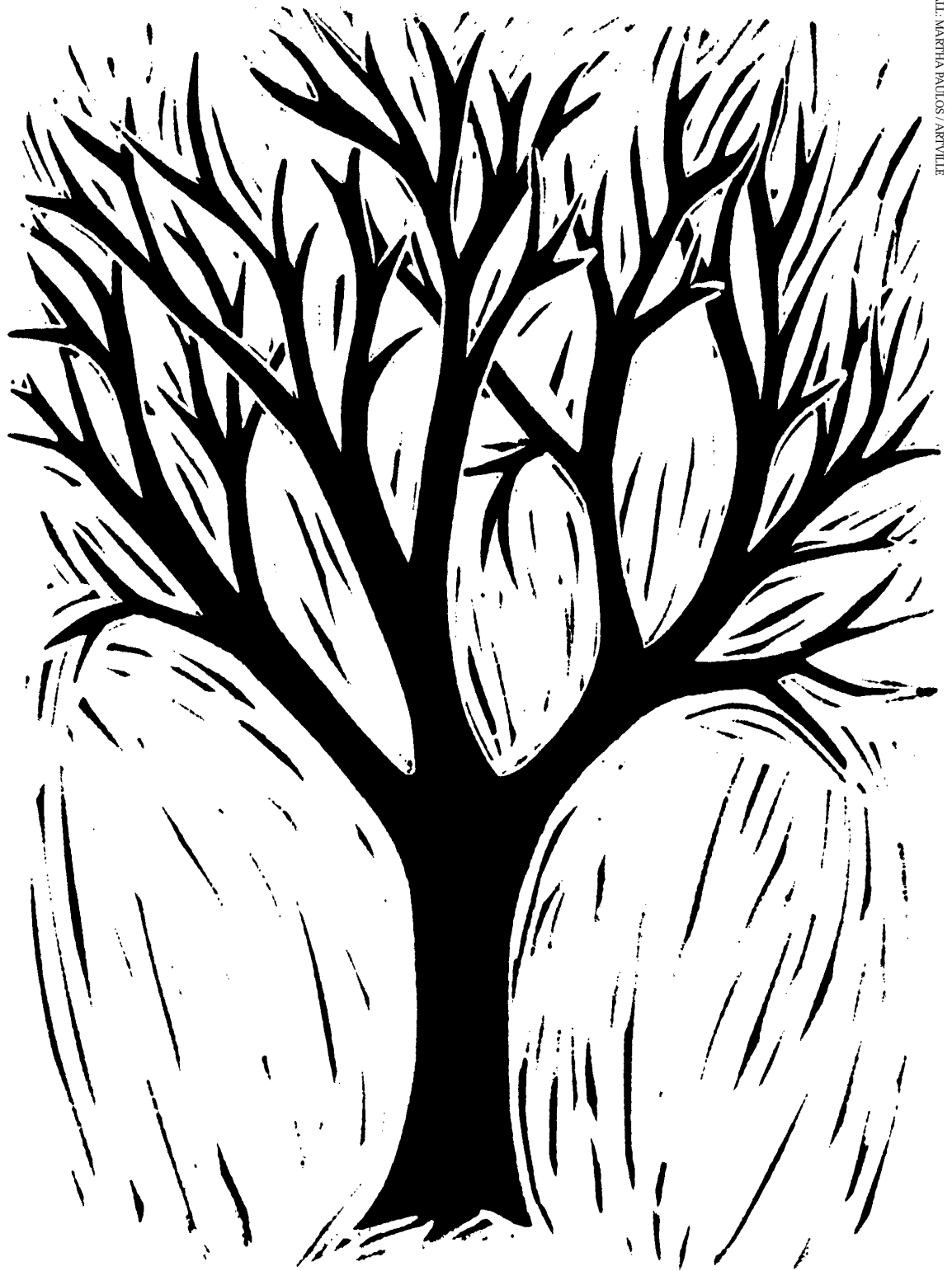

Three very personal perspectives on death offer insights for both patients and doctors. Sharing their stories are the widow of a DHMC cancer patient who died a few months ago; a faculty member who has considered and studied the care of dying patients; and a DMS alumna whose own experiences with illness have affected the way she practices.



AL MARTHA PAULOS / ARTVILLE

Facing death

Acknowledgment of loss

By Megan McAndrew Cooper, M.S.

Cancer patients frequently report that at the end of their lives, when there is “nothing left to do,” they feel abandoned by the doctors who, up until that point, they had thought of as engaged, caring, compassionate providers of care. It is a terrible feeling, being abandoned, and the end of life is a terrible time to feel it.

My husband was diagnosed with metastatic colon cancer in October of 1995. His first oncologist, whom we chose upon advice from friends with contacts in DHMC’s Norris Cotton Cancer Center, was a very young man. At our first meeting, in what I came to think of as a preemptive strike, he told us that “all my patients die.”

I do not think that he meant to be cruel to us, but to protect himself. He did not want us to see him as someone who could save my husband’s life, but as someone who would oversee the management of his disease’s inevitable progression.

I think that the young oncologist wanted, at that first meeting, to cut to the chase: in the end there will be nothing I can do for you. I think he wanted to inoculate himself against the pain of the moment at which we would all realize that there was nothing left to do and at which we would no longer be able to think of him as someone who wanted to help us but as someone who had tried but now had to give up.

Clint lived a long time, compared to others with his diagnosis—almost four years from the October afternoon I had to drive home to tell him that, contrary to his doctor’s expectations, the cancer that had been found on a routine examination of his colon had colonized his liver and spleen. There was time, in those four years, to try resection of his colon, new and established chemotherapies, experimental chemoembolizations and hyperthermia treatments of the main tumors in his liver, and radiation therapy for the tumors that grew in his spine and hip.

He was treated by a parade of providers: surgeons, oncologists, interventional radiologists, radiation oncologists, clinical nurse specialists, and his primary-care doctor, among others. Each began with the promise that they would do their best for

him; it was easy to see that each believed in the value of what they were offering him. Each treatment might work. Yet each treatment, ultimately, failed.

And with each failure there was abandonment. It was not always explicit, or even unfeeling. Some held his hand, or put an arm around his shoulder, as they delivered the bad news: the treatment had failed to reduce the size of the tumor, or the side effects were too drastic to continue.

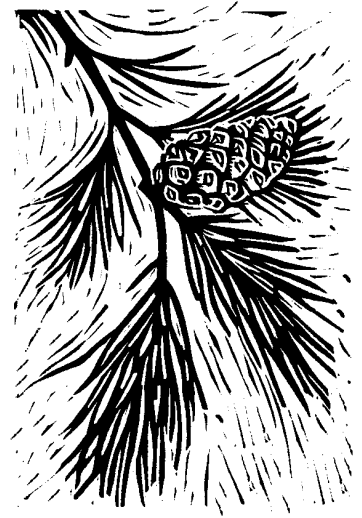
I also do not mean that these doctors—who were, almost universally, kind and thoughtful people—shrugged off the pain of the news they were delivering. I mean that they knew there was nothing else they could do to effect a cure, and so their relationship to Clint changed from helper to concerned but powerless friend. They had become like the rest of us—well-wishers who had no way to help.

I stood one evening outside Clint’s hospital room, which was next to the nursing station on the medical oncology ward. He had been admitted so he could get treatment for the side effects of the radiation therapy he had been given in an attempt to control the pain in his spine and hip. The attending oncologist was talking to a group of residents just around the corner. He briefly described Clint’s history and his current treatment. “This guy is at the end of the line,” he said.

I know that I was not meant to hear that comment, nor was Clint. But it was said. Among themselves, doctors can acknowledge that there is such a thing as the end of the line for someone who has received every available treatment, whose cancer is about to overtake even the strongest will to live. But at that moment there is, I think, the opportunity to make sure that acknowledging defeat in the battle is as painful for the caregiver as it is for the patient and his or her family—that we share, as human beings, the same despair, although we experience it in very different ways.

Clint was something of a pet in oncology, I think, because he lived so much longer than he was supposed to. A lot of people got a chance to think that they were, for a change, succeeding in holding death at bay a little longer.

But when it became obvious that his good luck would not hold forever—when he became jaundiced and began to walk with a cane; when I had to take him to appointments, or up the mall for a sandwich, in a wheelchair instead of on foot—the air changed. Everyone, from receptionists to doctors to hospital employees who had once been my colleagues to friends at parties, backed away from us. There are a great many ways to do this: not meeting one’s eye, not seeing someone standing in line



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I regularly saw ICU patients and their surrogate decision-makers preclude a good death through choices of therapy that were based on denial, ignorance, and fear. I saw physicians caught between patient or surrogate choices that they felt bound to honor and their own strong sense of appropriate care.

a few feet away, not talking any more about fishing, but only about whether you have talked to the hospice nurse.

When Clint's first oncologist left Dartmouth-Hitchcock, we chose an older doctor, one who has traveled this road countless times. We were graced to know him; he is a good doctor and he was a good friend to both of us, one whose humor matched Clint's and whose concern for him as a patient lasted until the very last days of Clint's life.

But finally there was a visit when he too detached, stopping by briefly and then excusing himself from the room. He saw Clint again, but they did not talk about summer vacations or the size of the fish they alleged they had caught. Because he had not protected himself from the beginning, he had to withdraw at the end, when such a separation must have cost him far more.

He did not say "This is the last visit" or "There is nothing more I can do for you" or "You will die soon." But he was sad, and we could feel that he was sad. It was a wonderful gift to know it.

So we experienced it twice, the feeling of being "abandoned"—once by someone who defended himself from the start against the pain that he knew would come; and later by someone who withdrew, just perceptibly, at the very end, when the burden of losing yet another battle became overwhelming.

In the days before his death, I too had hours in which I abandoned Clint, when I thought I could not bear any more suffering and when I prayed for him to be gone so the pain of losing him could replace the seemingly endless wait for his death. That abandonment felt, for me, the way it must have felt for all those doctors and nurses who had had to abandon hope that they could make him well again. It was agonizing.

If it were possible to go all the way to the end of life without those abandonments, I think we would all choose to do it. But not many of us can. I think, however, that it can be better than it so often is—not by changing our feelings, but by acknowledging them.

This is what I want to say to doctors: I think you should acknowledge, to yourselves and to your patients, that there is a moment when you will have to detach from the person who is dying, because you are human and because it is human to feel this as a moment of loss and despair. It should hurt to lose a patient for whom you have tried so hard; if it doesn't, you are missing something that a doctor ought to have.

So at the end of our lives, when there is nothing else that you can give, give us this: an acknowledgment of your own loss.

Finding meaning

By Thomas J. Prendergast, M.D.

How does a pulmonary and critical-care specialist become interested in palliative care? In my case it was through pediatrics, oddly enough.

During my third year of medical school at the University of California at San Francisco, I was assigned for three weeks to the inpatient pediatric hematology-oncology service at Moffitt-Long Hospital. It was a busy referral service that treated many patients with unusual tumors or recurrent disease. Nearly every patient was on a research protocol. The attending physicians were highly competent, and they cared about their patients, but I found working with so many dying children to be very distressing. To make things worse, I had a six-month-old baby at home.

At the end of the rotation, I asked one of the senior attendings how he could work in a setting permeated by the death of children. He reminded me that he had been witness to remarkable advances in treatment that now cured many who would have died earlier in his career. He then went on to acknowledge the emotional toll of seeing pediatric patients die and described how he had reconciled himself to it. He told me that he did not just treat kids with cancer, he cared for families. His responsibility as a physician was not only to the dying child but also to the surviving parents and siblings. If there was a tragic loss, then he tried to shepherd the family through that tragedy, to make it possible for them to grieve, and, sometimes, to find meaning even in the death of a child.

Superb clinician that he was, his answer planted two seeds. He emphasized his commitment to aggressive therapy but challenged me to broaden my vision of the physician's responsibility in those cases when medicine cannot cure. I didn't know it at the time, but he was teaching me the basics of palliative medicine. I began to glimpse the wisdom of his answer when, as a resident, I became interested in critical-care medicine. Intensive care units exist to give people a chance to survive fatal illnesses, though of course some will die in the attempt. When patients recover, it is exciting and uplifting. When they do not recover, patients and physicians may be faced with difficult decisions regarding limitation of life-sustaining therapies. I regularly saw ICU patients and their surrogate deci-

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sion-makers preclude a good death through choices of therapy that were based on denial, ignorance, and fear. I saw physicians caught between patient or surrogate choices that they felt bound to honor and their own strong sense of appropriate care. It seemed that physicians often understood the consequences of patients' choices without understanding the reasons for those choices. Indeed, it seemed that acquiescing to patient choices was a way to avoid discussing difficult end-of-life issues. This unwillingness to engage patients and surrogates in the process of decision-making led to overtreatment that neither party wanted.

Now, as an attending physician with responsibility for ICU patients, I have a greater appreciation for how the ICU environment—a place where uncertainty is everywhere, the stakes are very high, and emotions are on edge—makes communications difficult at exactly the time when they need to be carefully nuanced.

Palliative care offers several potential solutions to this dilemma. One theme in palliative care is its emphasis on improving communications. Traditionally, physicians are trained to see their interactions with patients and families as primarily information-based. Palliative care looks at discussions between clinicians and patients or surrogates as conversations; that is, each party brings to the interaction emotional and personal factors that are crucial to mutual understanding. For instance, by focusing on a concrete decision over resuscitation status or continued life support, physicians may neglect the emotional context without which patient/surrogate choices seem irrational. Palliative care holds that it is right to begin a discussion about dying while you are still trying to save someone's life, just as it is proper to broaden the discussion to include why people make the choices they do.

Death in an ICU is occasionally immediate and unexpected, but most often it is anticipated and managed through limits on interventions. Most intensivists are aware of the limits of their technology and many are adept at handling decision-making with families. However, the possibility that death may present opportunities for growth and reconciliation is still overlooked in ICUs. A good ICU death is one that happens quickly, once a consensus forms that cure is no longer possible. Opportunities to participate and to enrich the patient's and family's experience too often go unrecognized and are lost. This is a second area where palliative care has much to teach intensivists.

As my pediatrics attending suggested in a slightly different context, palliative care challenges us to find possibilities for grief and meaning in the face of untimely death.

The best medicine

By Elizabeth Tucker Marshall, M.D.

It was a rainy Pacific Northwest day, about five years ago, and I was discussing with a DMS classmate the revival of our humanity as physicians. I'd had a mitral valvulotomy two years before and was now in bed with a long-term IV access line in place, halfway through a course of antibiotics for bacterial endocarditis, an infection in the valves of the heart. My friend had just the previous day had to tell a patient—a 37-year-old woman—that she had stage-three breast cancer. I recalled similar moments, when I had been the bearer of heartbreaking news:

"You are HIV-positive."

"You are pregnant as a result of the rape."

"Your son has fulminant hepatitis."

Et cetera.

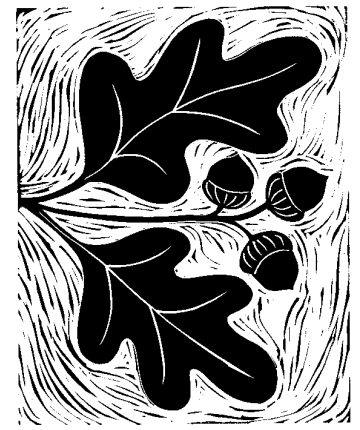
We agreed that medical training often neglects the healing we do as physicians—the healing, that is, that happens not with our intellects or our techniques but with our very selves. Medical training entails much use of the word "manage." We manage the lines, the vent, the meds, the illness, the patient. I wondered if we even believe we can manage the soul. It is in a simple, immutable fact—that we all go to the grave, we all are "ashes to ashes," we all were born into the same condition of mortality—that we physicians are like every one of our patients. And it is from this universality that we can offer our patients the greatest solace—in a realm in which we have no power, control, or ability to manage whatsoever: the realm of the soul.

Recent research on religion, spirituality, and prayer as part of the healing process indicates that these avenues are vital and curative for those who make use of them. Why is it that faith is as important as fact, whether it be faith in God, in gin-soaked raisins (a sure cure for arthritis, according to one of my patients), or in some other nonscientific entity? Is it as important to treat the unseeable soul as the concrete body? And if it is, how do we as medical professionals go about doing so?

My Uncle Len, now almost 80, trained as an internist in the days before everything. Before ventilators, central lines, defibrillators, a host of antibiotics, pacemakers, and calcium channel blockers. In those days, physicians-in-training sat with the dying and with the families of the dying. Attending physicians actually attended the bedside. They

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Elizabeth Marshall, a 1987 graduate of Dartmouth Medical School, is a family physician in Everett, Wash.



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